

Alabama Department of Rehabilitation Services

## CRS *parent connection*



SUMMER 2017

## ADRS, Easter Seals open Tuscaloosa facility

#### by Ryan Godfrey

Easter Seals West Alabama (ESWA) and the Tuscaloosa offices of the Alabama Department of Rehabilitation Services (ADRS) recently hosted a ribbon-cutting celebration for their new state-of-the-art facility.

The new building – located at 1400 James I. Harrison Jr. Parkway Drive East – places all of the ADRS programs in Tuscaloosa under the same roof, providing easier access for consumers.

The 56,000-square-foot complex features three floors, with Alabama's Early Intervention System offices and Children's Rehabilitation Service offices and clinic space occupying the first floor and office and meeting space for Vocational Rehabilitation Service and State of Alabama Independent Living on the third floor.

ESWA – which built and owns the building – occupies the second floor.

ADRS joins ESWA in a unique publicprivate partnership to increase current services to individuals of all ages and disabilities, expand workforce development efforts in the region, and create new opportunities for employment for persons with disabilities.



West Alabama consumers cut the ribbon on the new facility



Above, the 56,000 square feet of office space houses ESWA and all four major ADRS programs

Right, the interior of the new audiology booth



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### From the Director's Chair

Melinda

Hello Parents,

As FY2017 enters its last quarter,

July 1 - Sept. 30, I want to share a few district-level changes with you and remind families of the possibility of upcoming service changes.

Tuscaloosa/Selma **CRS** District Supervisor Barbara S. Hankins retired from ADRS on May 31. Barbara has been a champion of Maternal and Child Health services throughout her professional life. She began her career as a social worker in 1980 and had 10 years of experience in various departments with the state when she joined ADRS as a social worker in 1990. Barbara quickly advanced to administrative positions in the CRS state office, serving as social work program specialist and pediatric traumatic brain injury (TBI) coordinator before taking the helm as district supervisor. Barbara never gave up on her vision of having state-ofthe-art facilities for children, youth, and families in the Tuscaloosa/Selma district, and today we owe a debt of gratitude to her for staying the course until that vision was realized.

If you are a recipient of CRS services in this district and have not attended a recent clinic, you will be in for a huge treat at your next visit. Be sure to note the address changes. Barbara's footprint will be recognized for years to come in many aspects of ADRS/CRS programs. Please remember to thank her as I'm sure you will be seeing her continued work in your communities as her advocacy continues.

At the same time, you can expect that the services offered in the Tuscaloosa/Selma district will continue to reflect strongly on family-centered care under the leadership of Lana Langley as the new district supervisor. Lana began her career in the Fayette County School System in 1999 as a developmental teacher, later becoming a preschool intervention service coordinator and then speech-

language pathologist. Lana has been a speech-language pathologist at ADRS in the Tuscaloosa/Selma district since August 2015, and we are very pleased to welcome her as the district supervisor on June 16. Please plan to attend your local Parent Advisory Committee meetings so that you can meet Lana and other district supervisors in your areas around the state.

Finally, the shift to regional care organizations (RCOs) has once again been scheduled for implementation beginning Oct. 1, 2017. It's important that you become familiar with this new system of care as RCOs will coordinate the health care of Medicaid patients in each region and will bear the risk of contracting with the state of Alabama to provide that care. Your child will likely receive services directly through an RCO rather than through Medicaid. Medicaid will notify you of changes at least 90 days in advance, so expect notification and information about education some time during the summer months. Medicaid wants recipients to continue to receive the same or similar services, so services you currently receive at CRS will continue. In addition, we meet with our Medicaid partners regularly to discuss the services we provide in an effort to assure that the quality of services received by children and youth with special health care needs (CYSHCN) remains the same throughout

I encourage you to learn more about RCOs by going to the Medicaid website, www.medicaid.alabama.gov, and clicking on "Managed Care" on the homepage. CRS staff in your districts will assist you through this transition.

Have a great, safe summer!

Melinda Davis CRS Director



# 'Sit With Us': How a 16-year-old girl used her bullying experience to help others

Reprinted with permission from PACER Center, Minneapolis, MN, (952) 838-9000

Carolyn Hampton of Sherman Oaks, Calif., had always planned that her daughter, Natalie, would attend the girls middle and high school she herself had graduated from. Carolyn looked forward to Natalie, who had had a "great" experience in elementary school, attending the school she had loved.

#### A difficult start

It didn't work out that way. "At first, it seemed like she just wasn't fitting in," Carolyn said. Natalie wasn't making friends. Some of the girls verbally bullied her, and she ate lunch alone every day.

Then in the spring, Natalie was physically attacked. "She was slapped around and tripped," Carolyn said. "She had fingernail marks on her face and bruises on her legs."

A week later, a different group of girls bullied Natalie. "They took her laptop and played keep away with it in an area with a brick floor," Carolyn said. "They knocked Natalie down, pinned her to the ground and stood on her head."

Carolyn was shocked that the school's administration did little to stop the bullying. The school didn't seem to care about Natalie's experiences, and the students involved faced no consequences.

Meanwhile, Carolyn was troubled by the changes in her daughter. "Natalie went in to the school as a kid who was happy. She loved school and academics. After the bullying began, she started to say that she was sick to avoid going to school. She was withdrawn and shrunk into herself. It was so sad to see."

Over the summer, Carolyn tried to help Natalie form some friendships with classmates. Though that didn't work out, the Hamptons tried to be



Natalie Hampton with the 'Sit With Us' app she created

optimistic for the next school year.

#### The bullying continues

When school started again, so did the bullying. Sometimes it occurred after teachers praised Natalie's work. "Natalie is a good student. Teachers would hold up her work as an example," Carolyn said.

Things came to a head when Natalie was the only student in her class able to complete a difficult physics lab. Another student threatened to stab her in the neck.

Natalie was developing physical symptoms that Carolyn thought pointed to post-traumatic stress disorder (PTSD). "When she was in a room, she would scan the exit," Carolyn said. She wanted Natalie to change schools, but after her theatreloving daughter gained a good role in the school play, they postponed the decision. "We wanted to take the time to make sure the next school would be better."

Natalie hoped to make it through the

school year without another bullying incident. Then she saw a group of girls who had bullied her, bullying a younger student. "The kid looked terrified," Carolyn said. "Natalie put herself between the group and the younger girl, and yelled at them to back off."

After she transferred to a new school, "She fell in with a nice group of friends," Carolyn says. Things were better from the very beginning.

#### Choosing to help

Even though she was happy in her new school, Natalie couldn't forget her experiences. She remembered what it was like to eat lunch alone everyday, and she wanted to help others in the same situation. The "Sit With Us" app was born.

The reasoning behind the app is simple: Students volunteer to be "ambassadors" and host "open lunches" in their school cafeterias. Other students use their phones to find a place to sit at lunch, without having to risk public rejection.

Word about the app spread, and Natalie was sought out for media interviews, starting with National Public Radio's "All Things Considered." Soon she was interviewed by the Today show, the Washington Post and Us Magazine.

The media attention was bittersweet, Carolyn said. "Natalie had to constantly relive what had happened to her." Natalie is willing to be interviewed because she believes that eating lunch alone everyday made her even more of a target for bullying. She wants to help end the isolation.

"Sit With Us" is currently available for iOS (iPhone), and an Android version is in the works.



## Cool Stuff: Chill with these hot toy ideas

by Ryan Godfrey

All kids have different learning styles and abilities, so it's important to find things to spark their interest and support their individual needs.

Toys that aim to reach, teach, and delight children with special needs make your job as a parent just a little bit easier.

The key to shopping for toys for your child is to find something that is both appropriate and matches your child's unique abilities and skill levels.

For instance, the Gears Gears Gears Motorized Spin & Glow building set from Learning Resources (\$55) might be perfect for children with autism, or anyone who like things that spin, move, or show repetition.



Toys with colorful moving parts are a good option for children with autism

This particular set has a motor, lights, and glow-in-the-dark stickers.

For kids who can benefit from tactile and sensory learning, *Educational Insights Playfoam* (\$8 and up) is perfect for no-mess crafting that won't dry out. Like Play-Doh, the toy is perfect for sculpting and creating, but unlike Play-Doh, it won't stick to carpet or clothing.

Legos are always a popular toy with children who like to build, but the small parts are often problematic for children



Playfoam is a fun way to creatively introduce tactile and sensory learning into play time.

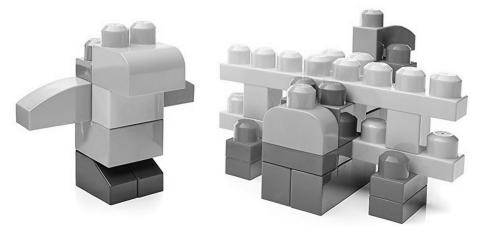
with cerebral palsy.

Larger building bricks, like *Duplo* or *Mega Bloks* (\$15 and up) fit the bill for creative playtime. The building toys are also well-suited for playtime with the younger set.

Finally, Toys-R-Us has developed an extensive guide to assist in buying toys for children with special needs. The Toy Guide for Differently-Abled Kids [www.toysrus.com/shop/index.jsp?categoryId=3261680] has been

available for more than 20 years as a one-of-a-kind resource that offers toy recommendations based on research from the National Lekotek Center.

Because all kids are unique, regardless of ability, toys in the guide are not categorized by disability or age. Instead, symbols are assigned to each toy based on different skills. In this way, the guide helps parents choose toys to build or reinforce a variety of skill sets.



Larger building blocks, like Mega Bloks, are ideal for children with motor control difficulty



### When the special needs siblings don't play nice

Reprinted with permission from Complex Child e-magazine

#### by Jamie Sumner, parent

We took the kids to the park last week because:

- 1. It was fifty degrees and they needed airing out
- 2. They were out of school and crazy
- You can only go to Costco and the mall so much

The actual park experience had been great. I walked Charlie around the perimeter in his wheelchair, where he waved hello to every person, bench, and squirrel. Our twins ran rampant under wooden tunnels, through people's legs, and down (and up) all the slides.

We managed to fill up those couple of morning hours that feel just a tiny bit like parent purgatory before naptime. Everyone was happy and tired when we piled back in the car. I let my guard down, breathed out the breath that meant I could sit, facing forward for fifteen minutes without moving. They always sense when there's a perimeter break, like velociraptors.

Charlie started to cry and I turned to see his little sister, Cora, standing next to him with a book in her hand carefully avoiding my eye. My husband was buckling in Jonas, her twin brother, so she was free to roam the territory. The book was actually only three sad pages from Goodnight Moon (the rest had been sacrificed to car rides of yore). But they had been Charlie's three pages. He had been flipping through them contentedly before Cora's nimble theft.

Here's how it went down after the crying began:

**Me:** "Cora, was Charlie holding that first?"

Cora: Long pause. "No."

**Me:** "Yes, he was Cora. Now give that back to him."

Charlie continues to cry and point to the book and then sign more. From Cora, silence.



Charlie, left, plays in the neighborhood park with his younger brother, Jonas

**Me:** "Cora, do not make me say it again."

**Cora:** Looks to me then Charlie. She bends down and picks up a toy SUV whose battery died sometime in July. "No, he pointing to this. Charlie want this one." She actually reaches around his arm, outstretched toward the book, and plops the SUV in his lap.

Silence as I get out, climb in the back, give Charlie the book, and buckle/restrain Cora, whose screams reach the heavens.

**Me to my husband:** "I hate it when she treats her brother like that."

**Husband:** "They're only two."

Me: Pointed silence.

Most of the time the twins hug him and make sure he has his blanket/toy/book/water on his tray. They love to help push him in the wheelchair and walk him in to school. They could be the poster twins for special needs siblings. But man, it gets me when they fill his silence with what they want to hear. It seems meaner somehow, willfully ignoring his words when he can't fight back with his own.

I know the stories of the siblings of kids with special needs who seem to love in a different way with a more patient heart. I hope for this with the twins every day. But it's not always Hallmark over here. We get the uncensored version, too.

As I was sifting through my anger in the car on the way home from the park (mostly the Serenity Prayer on repeat), I realized that Cora's actions were better than mine had been lately. She was treating him like a brother, a brother whom she would manipulate any chance she could get. She'd do the same to her twin, Jonas.

It was me who was treating Charlie like he had special needs. To Cora, he's just Charlie, and that's how I want it to stay. After all, isn't that what I want the world to see too, Charlie – the boy – minus the diagnoses? If I'm going to preach equality and fairness in this family, I'd better practice it for all our sakes.

Of course, I'm still going to have to teach the velociraptors to share.

For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at rehab.alabama.gov/CRS and www.facebook.com/CRS.ParentConnection

### Building your own support network

by Melissa Murphy, guest writer PEAL Center – Pennsylvania Family Voices

We have all heard that it "takes a village" to raise a child. But what happens when you have to build that village yourself? Where should you begin?

When my daughter was diagnosed with a rare genetic syndrome called Williams Syndrome, I needed to learn how to navigate a new world of early intervention. I was already overwhelmed as the mother of two preschool-age children with a challenging career. Not only did I not know the answers to many of my questions, I did not even know where to look for answers. I needed help, and fast.

I started the way I would begin any new project – with research. I began on the internet, looking for support groups and any local and state resources that may be helpful. I sent many emails to folks I did not know; most responded immediately and were incredibly generous with their time and expertise. I soon realized I needed to build a support system that is a combination of the professional and personal.

#### **Professional Support**

Gather experts that know the system, know the program, know your child, and then rely on their expertise. We are fortunate in Pennsylvania to have myriad free resources that are available to help support your family, but it's not always easy to find out about how to access them.



Melissa Murphy with her daughter

If you have a trusted teacher or therapist, ask them what resources are available, and then call or email those contacts. I was amazed at how responsive the folks in Harrisburg were to my questions. I also participated in an incredible free training program through Temple University's Institute on Disabilities, which connected me with a network of professionals that could help my child.

#### **Personal Support**

But you also need personal support, especially other parents traveling a similar path. These people may be at your preschool, your church, or synagogue; neighbors; or moms you connect with online. Because my daughter has a rare diagnosis, Facebook has been an invaluable resource. I was able to connect with other moms who understood exactly what I was going through and who could offer reliable advice and support. And these virtual friends have become "real life" friends, some of the most meaningful

and supportive relationships in my life.

In fact, I asked some of my fellow mamas for their best advice – how they knew they needed more support, and how they built their own support network. Here is what they said:

- "I realized I needed more support when anger began to undermine my primary parenting goal, that my children should always feel loved and secure at home and know that they are worthy of kindness especially in their dark moments."
- "Connect ... connect! Find a small group of people that get it so that you don't feel so alone; it's so important to know you have someone whose (sic)been there done that and that you can feel comfortable reaching out to for support."
- "First and foremost, I cannot stress how beneficial it has been to have confidants (sic) who are going through a similar experience. It's the club I never wanted to be a part of but I am so glad to be a member now."

Remember, YOU are the expert on your child, YOU are their first teacher and YOU are their most important advocate. If you don't have the support that you need, you can't possibly meet your child's needs. Reach out and connect; there are many teachers, professionals and fellow parents just waiting to support you.

For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, susan.colburn@rehab.alabama.gov, or Jerry Oveson at 251-438-1609, oveson@bellsouth.net.



# CRS seeking young person to serve as statewide youth consultant

CRS is seeking a youth/young adult age 18-26 with special health care needs to support the Alabama Department of Rehabilitation Services/Children's Rehabilitation Service (CRS) as statewide youth consultant.

#### <u>Pay</u>

\$12/hour

#### Job requirements

- Age of youth consultant limited to 26 years
- Must be a CRS client or have received services from CRS
- Transportation may be needed periodically during work hours
- Travel within the state is a requirement, and on occasion, opportunity for out-of-state travel
- Ability/flexibility to work 10-12 hours per week. On occasion,

up to 24 hours per week may be necessary to attend meetings/conferences, etc.

#### Skills

- Ability to work independently and manage time appropriately
- Comfortable working one-onone with youth by phone, email, meetings, etc.
- Knowledgeable and comfortable sharing about own disability
- Willingness to learn more about disabilities
- Some experience using the computer and willingness to develop new computer skills
- Experience or willingness to learn to use other office equipment, i.e. copier, fax, etc.
- Good communication skills
- Experience in social media
- Responsible

#### Tasks

- Member of CRS State Office team
- Provides leadership to CRS Youth Advisory Committee (YAC)
- Provide informational article on issues
- Participate in local CRS office youth activities
- Assists state office staff with projects as needed

This position is supervised by the CRS state parent consultant.

To apply, send a letter of interest and resume to Lolita McLean, CRS State Office, 602 S. Lawrence St., Montgomery, AL 35401, or lolitamclean@rehab.alabama.gov.

If you have questions, call (334) 293-7133.

#### Consumer renovates CRS lobby for Eagle Scout project

#### by Emma Hereford, Gadsden CRS

Old tube televisions are certainly a thing of the past, but until recently, that is exactly what families found in the lobby of the Gadsden CRS office.

All of this changed when – as part of his Eagle Scout project – Alex Benjamin approached CRS staff about his desire to replace the TV he had seen sitting in the waiting room for at least 15 years.

Once Alex received approval from his troop to proceed with the project, he built a custom television cabinet with help from other Boy Scout troop members.

Alex also spoke at area churches to help raise funding for his project and set up donation boxes to collect new DVDs for the Gadsden CRS video library.

Thanks to the project, Alex was able to secure funds for a new flat panel



Alex Benjamin speaks at the Gadsden CRS lobby dedication ceremony

TV, a DVD player with more than 100 new videos, and a \$250 gift card to purchase additional items for the lobby as needed.

At the dedication ceremony, Alex said he wanted to do something to give back to CRS for the services and care he has received over the years.

Alex is a shining example of how

hard work and determination pay off. He recently made a 29 on his ACT and is looking ahead to attending college in the fall with a goal of one day working as a video game designer. After successfully managing his Eagle Scout project, his future certainly appears bright.

## Tuscaloosa CRS office honors consumer as Kids Wish Network Hero of the Month

Ashlyn Wilson, a CRS consumer from Tuscaloosa, was named April's Hero of the Month by the Kids Wish Network.

To celebrate the honor, staff in the



Tuscaloosa CRS office sponsored a party for Ashlyn and her family, complete with pizza and cupcakes.

Ashlyn, who has Down syndrome and bilateral hearing loss, loves cheerleaders and cheerleading, so CRS staff worked with Varsity Athletics Spirit and the ACE Cheer Company to bring cheerleaders from area schools, including the University of Alabama, Shelton State Community College, ACE Cheer Company, UCA Cheer Camp, Holy Spirit High School, North Ridge High School, Tuscaloosa Academy

High School, and Tuscaloosa County High School.

Varsity Athletics Spirit also donated a gym bag filled with goodies for Ashlyn and will be providing a custom-made cheerleader uniform for the youngster.

The Hero of the Month program cheerleader honors children



Ashlyn gets a lift from a University of Alabama

between the ages of 3 and 18 who have faced and overcome difficult circumstances. Hospitals and child care facilities throughout the entire country participate in the program.





Above, Ashlyn, seated right, poses for a picture with the cheerleaders who attended her celebration

Left, Ashlyn and mom Angela share a moment at the celebration



## Summit unites families, professionals

#### by Ryan Godfrey

More than 100 attended the seventh annual Family Voices Partners In Care Summit held recently at the Marriott Legends at Capitol Hill Conference Center in Prattville.

The two-day family/professional development workshop aims to strengthen networks between families and care professionals and spotlights current challenges to developing quality systems of care for children and youth with special health care needs and their families in Alabama.

The first afternoon of the conference was open exclusively to youth and families, providing a critical time for them to network and develop skills to take back to their communities.

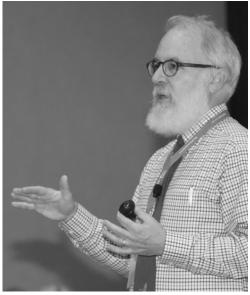
Day two of the summit featured a workshop designed to give families and youth and the professionals who work with them an opportunity to learn together, network, and identify strategies to help improve outcomes for children and youth with special health care needs.



Statewide Early Intervention Coordinator Betsy Prince takes a photo of, from left, Julie Beckett, Family Voices co-founder; Susan Colburn, state parent consultant; Melinda Davis, CRS assistant commissioner; and ADRS Commissioner Jane Elizabeth Burdeshaw

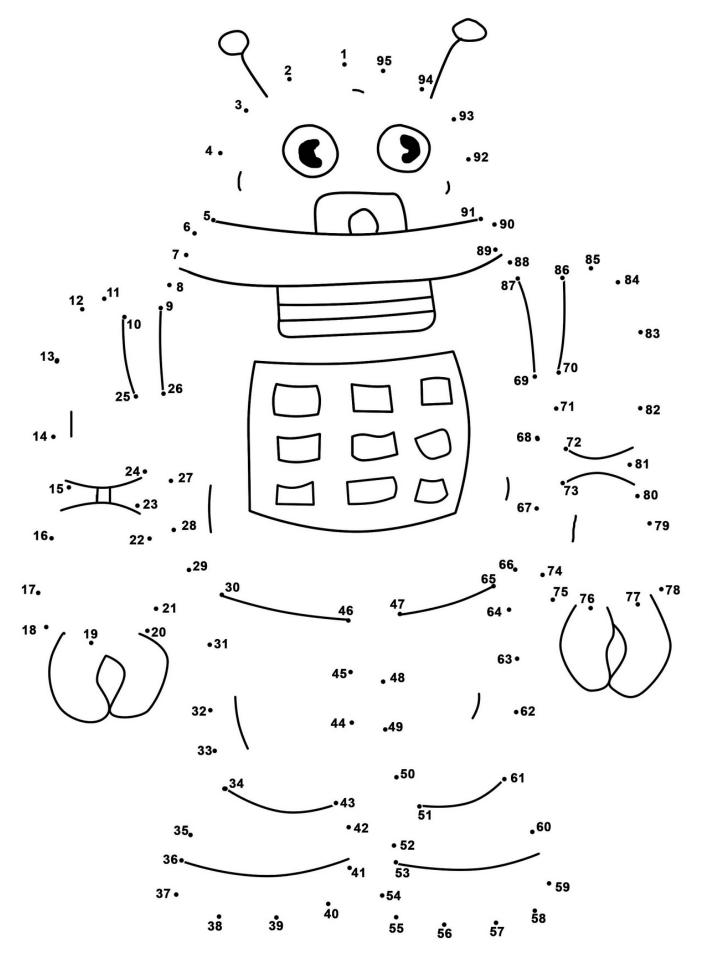


Kim Lewis speaks with a visitor to the Children's Rehabilitation Service exhibit table



Jim Carnes, policy director for Alabama Arise, provides an update on the current state of health care in the state of Alabama

## ROBOX DOX-XO-DOX



## Opelika CRS celebrates summer with annual 'School's Out Bash'



Children and parents enjoy train rides at the Opelika School's Out Bash

#### by Ryan Godfrey

The Opelika Children's Rehabilitation Service office kicked off summer with the annual School's Out Bash for

children with special health care needs.

Some 200 families from



A parent and child visit with a firefighter

families from the Auburn-Opelika area attended what has grown to become the year's biggest event for the east Alabama office.

Sharon Henderson, parent consultant for Opelika CRS, coordinated the event, which featured music, pony rides, a cupcake walk, train rides, face painting, bubble art, therapy dogs, resources, a karaoke competition and so much more.



A child tries his hand at the dunk tank, one of many activities at the event



Children's Rehabilitation Service Alabama Department of Rehabilitation Services 602 S. Lawrence St. Montgomery, AL 36104

#### PRESORTED STANDARD U.S. POSTAGE PAID

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#### Oct. 23-25, 2017

#### 33rd Annual Early Intervention and Preschool Conference

**Description:** The Early Intervention and Preschool Conference is a two-and-a-half day event for families of children birth to age five with special health care needs and disabilities and professionals who work with them. The conference is sponsored by Alabama's Early Intervention System and United Ability. Keynote and concurrent sessions are planned based on surveys, suggestions from previous conferences, and national/state priorities. This year's conference will be at the Westin Hotel in Huntsville.

Information: Jeri Jackson, 334-293-7088, or www.ucpalabama.org/conference

Local PAC meetings:

Check your local CRS office for dates
and times of meetings in your area.